

## **On the experience of combining participant observation and interviews with intellectually disabled informants during long-term engagement; the pros and cons.**

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### **Introduction**

During the last couple of decades people with intellectual disabilities have been participating as informants in research, but still there is a lack of knowledge about how people so labelled perceive themselves and experience their daily lives. In my study I wanted to study the everyday life of young adults with intellectual disabilities and to look into how the label intellectual disability might influence their self-understanding. One challenge was to really get to know the participants and at the same time keep a distance, in order to be able to frame the perspectives of the informants in a theoretical and societal context.

Literature about intellectually disabled people as informants recommend that one uses different methods in order to be able to shed light on people's lives from various perspectives. I wanted to spend time with my informants in order to develop a relationship based on confidence. For that reason I recruited few informants and chose a long term qualitative ethnographic approach; participant observation, field conversations and interviews. I had in mind that parents and professionals often speak on behalf of persons with intellectual disabilities and therefore I chose not to gather information from anyone else than my seven informants. They were four women and three men, and from 18 to 30 years old at the beginning of the study. I spent time with the informants over a period of two years. I visited them at home, at their work places and in their leisure time. When I visited, I also met parents, friends and professionals, and I observed how my informants related to them and sometimes talked to these persons informally. My main interest was to gather information from the seven persons that had volunteered to participate in the study.

I have named the seven participants in the study and the names I use in the presentation are not their own names.

### **Methodological approach**

According to Kvale (2001) some people are not easy to interview. However, he encourages researchers to motivate and to arrange for the persons' narratives and says that if one's efforts prove successful, interviews can be rich on information almost regardless of who the informants are. He also gives advice that the researcher should be qualified as an interviewer, and be familiar with the field where the interviews take place. It is my experience that it is possible to interview persons with intellectual disabilities. However, it is an advantage to have some experience in speaking with persons with intellectual disabilities and that one is familiar with how they live and work. Then it will be possible to ask in concrete ways about their daily lives and use one's knowledge to create a safe interview situation. It is important to use a simple wording, and one also has to improvise sometimes in order to talk about the same themes from different angles. This is not only the case when one is interviewing people with intellectual disabilities, but is characteristic for all good interviews. One thing to have in mind is that one should not underestimate people with intellectual disabilities. My experience is that it is possible to reflect together with people with them about their experiences. It is also my experience that the interviews become even richer when the researcher has first hand

information about the daily lives of the informants. This is possible when one combines interviews and participant observation.

Participant observation often takes place with a local society, a group or community as the research unit. I had a somewhat different approach. I started with recruiting informants and followed each of them on different arenas. My focus was the individuals in context, not the context per se. In many ways I was familiar with the arenas that I should visit during my study. For many years I had been working with planning services for people with intellectual disabilities, and I knew about their situation. On the other hand, I had never worked in people's homes, work places or in leisure activities and did not have personal knowledge about what was really going on. This means that I was both a stranger and a relatively well informed person. This combination of strangeness and closeness was important when I approached the different arenas. I had to build up sensitivity about the field and also work on my pre-understanding in order to be aware of what I could risk taking for granted.

When I visited my informants in their homes and no one else was around, there were opportunities to carry out formal semi-structured interviews. In the interviews we could reflect about our experiences from other settings, talk about specific episodes, and I could ask about things I might have been wondering about. During the interviews I also had the opportunity to ask about topics that I wanted to hear the young persons' opinions about; as what is it to be an adult or what they were thinking about intellectual disability. In short, the observations provided me with an overview of what the daily life was about, while the interviews added depth and reflection. There were even lots of opportunities during the observation period to talk with each of the informants; for instance when we were working together or at lunch breaks. These conversations were more directly connected to the situation; for instance about what was going on, the meaning of work, to have success in work life and also about other topics as friends, family or activities.

### **Informed consent**

In research one has to face several ethical dilemmas and questions, for instance questions about informed consent. People with intellectual disabilities belong to a group that is described as people with reduced ability to give their consent. For me it has been very important to make sure that the participants really understand what their participation is about. In addition to an ordinary written consent I tried to use what Smythe & Murray (2000) describe as a processual consent. They write that consent should be regarded as something that is not given once and for all, but as something that should be negotiated throughout the whole research project. This means that one has to reflect during the whole process about whether the informants participate voluntarily. I have tried to do so by always making appointments asking whether they want me to come and visit. Sometimes questions about consent have turned up, as for instance when Inger asks: "Why do you ask about that?" In situations like that I had the possibility to remind her about my role as a researcher and what we had previously agreed about. Sometimes other people would ask my informant and me about our relation. Then I could turn to my informant and ask if he or she would tell the other person. Thus, it was possible for me to find out if the informant really had understood what they had accepted to take part in.

### **Participant observation**

One advantage when using participant observation is that it is possible to include people who do not talk too much or have problems expressing themselves verbally. This was very obvious

when I visited the work places. Kjersti does not say much, but by her speed at the work place I could see that she is a very clever worker, even without her saying anything. I could also see that she liked to help others who did not work so fast, and that she seemed to value what she was doing. In an interview, Kjersti would probably not have found the words to describe her efforts and likings. Now she was able to show me, and I could ask concretely about the different operations she was performing. This gave me a comprehensive picture, not only of what Kjersti was actually doing, but also about how she felt about both her work and her colleagues.

Henrik is another example. He could show me how clever he is when handling the wood cutting machine. I could also observe that he was able to work alone while most of his colleagues needed some assistance when they used the machine. If Henrik had told me only in words that he was cleverer than many of his co-workers, I would not have known if that was only bragging. Now I could see for myself that his self-presentation as a clever worker was rooted in his real competency. I could also observe that the leader gave Henrik more freedom than other workers. He could be left alone and still do his work. Thus he marked his independence and skills in a convincing way. What I could see when I observed Kjersti and Henrik as workers, was that their work was an important factor of their self-presentation. As workers they demonstrated competency and also work ethics as they both lived up to ideals about doing one's best. This would have been hard to grasp in an interview setting.

Another positive element about participant observation is that it is not researcher lead. First, one has to relate to the setting as it is. As researcher one is a visitor and has to follow the rules of the setting. Second, the participants are observed in a field that they are familiar with and where they are the ones to know what is usually going on. They may take initiatives to tell about what is important to them, and they can introduce the researcher to both the field and the people present. In a way, the informants have a degree of power in the situation. For instance they can turn away from the researcher, find another place to sit or stay or find somebody else to talk to. Luckily, I did not experience much avoidance during my observations. However, I knew that it could be tiresome for the informants to have me around for hours. Therefore, I sometimes took a break, went away for a little while or talked to somebody else. Some times I understood that it had been enough, for instance when Grethe glanced longingly at a friend or when Henrik in a determined way declared that: "I have to go to the toilet, see you later." At such occasions I could leave and return again another day.

Doing participant observation means that one is close to what is going on in peoples' lives. The participants are observed and interpreted in context. One also has the opportunity to be able to ask about things when they actually happen. One observes places, persons and processes. By places I mean where things happen; in my case the work places, homes and arenas for leisure activities. I tried to observe the whole environment; decoration, furniture, equipment and ask myself what this place would signal about the people who use to be there. For instance, I tried to observe whether a work place looked like a real work place or if the purpose of work seemed ambiguous or make believe. I also observed the persons, especially my informants but also all the persons at the setting; what they did, how they were dressed and how they interacted. The mutual interaction between the persons at a setting is part of the processes that I observed. Other processes could be schedules, rules and routines. I tried to find out how people reacted to the material environments, each other and the processes going on between the participants of the setting. It is a demanding task to grasp the totality of a setting. Luckily, I had the possibility to spend to visit several times and could have my main focus on environment one time and interaction another.

When I observed interaction I had to have in mind my relation to the third party. That is persons who are observed and commented on without having had opportunity to give their informed consent about participation. I have tried to protect every other person with intellectual disability that I refer to by not mentioning them by name or characteristics. I have mainly referred to them in their interactions with my informants but it would have been impossible to exclude them totally because it was important for me to observe and interpret how my informants related to others. Helpers are third parties as well. Sometimes I have observed helpers in interactions with my informants where my interpretation has been that the interaction did not support my informants. This may have placed some of the helpers in a negative position. But I have simultaneously presented examples of supportive relationships between the informants and their helpers and I hope both sides will shed light on what is going on in helping relations. I have tried to interpret the acts of the helpers in light of structural frames like shortage of time and the organisation of the services. My intention has been to be critical and at the same time not offend.

I must add that as an observer, I was also a participant in what was going on at the settings. I therefore had to reflect on my involvement and my repertoire of roles, both the ones I choose and the ones I was ascribed. I had opportunities to switch between different roles and different degrees of participation, but I was also limited by the roles that others placed me in. I had to think about how I was perceived by the informants, by other persons with intellectual disabilities and the helpers. For instance Frida told me at our first meeting that she knew that I was going to study how people with intellectual disabilities were leading their lives. She then gave me a role as student because she knew that she could teach me about her life. To Henrik my role as a researcher was the most prominent. He comes from a family of academics and my role as researcher made sense to him. The helpers too had questions about who I was. For instance two helpers once asked me if I had met people with intellectual disabilities before. When I told them about my experience they seemed relieved. They may have perceived researcher as people who are distant from realities. Their motives might also have been to try to protect the people that they were working with.

In addition I had to reflect about how my participation would affect what was going on. One thing I wondered about was the way helpers related to the informants when I was present as if the informants were not really there. For instance they could tell me about the informant when he or she stood next to me, or they could undermine the self-presentations of the informants seemingly without relating to what they might feel about losing face. This told me that I sometimes was perceived as another helper and it at the same time informed me more about the lack of equality in the helping relation.

I spent relatively short hours at the different arenas. As the observation period lasted for approximately two years, I was able to gather information about holidays, seasonal variations and special events like Christmas and Easter. In my first observation period I visited the informants relatively often in order to get to know them. Then I withdrew for a period in order to analyse my data before I prepared for a new observation period. Fangen (2004) calls field breaks and writes that it may be useful to withdraw in order to gather good field notes. A break can mean that one is able to reflect and avoid being "blind" about what is going on at the field. I felt a need for breaks because I was observing at several different arenas and got many and various impressions. I also thought that my informants would need break from me being around and may be they would be happy to see me again after a while. I needed to sort my field notes, reflect on what I had found and prepare my next move in order to be able to

focus on things I could have missed out or did not understand at my early visits. During field breaks I was able to refine my focus and look for more details and also things that I had not expected to find.

Several of these advantages can also be experienced as problems. It is for instance not easy always to discover whether one really is accepted as participant or whether one is experienced as an intruder. Questions about the use of the toilets, where to sit at lunch breaks etc needed thorough consideration. One always has to remember that one is staying in arenas that belong to others. One therefore has to be humble and show respect both to the setting and the people there. However, one has to live with some feelings of not being welcomed all the time. Even if one has an appointment, one can never be sure that the informant really wants to speak with you. I had to negotiate through the whole process, about access, about my roles and about how I was supposed to behave. This is challenging and often tiresome.

There were also disturbances. For instance some of the persons with intellectual disabilities seemed to think that I was an interesting person and wanted to have my attention. This might disturb for instance the work that was going on, and could interrupt my contact with my informants. I had to balance between not rejecting people who wanted contact and not disturb the ways things used to be. I tried to have in mind that some people with intellectual disabilities are not always “seen and heard”, and I tried to be inclusive without too much fuss being made. When I spoke with my informants I had to have in mind that others could hear what we talked about and even join the conversation. During the observations I was therefore careful not to talk about difficult themes or very personal matters. Such subjects could be talked about in the interviews.

However, my experience is that not all arenas are suited for doing participant observation, at least not when one is interested in only one person at a time. Most work places were well suited as well as places like a dance club because many people were present and they all participated in different jobs or activities. I did not accompany my informants at more informal events, for instance when they went out in the neighbourhood. A reason for this choice was that few of my informants went out alone without support from helpers. If I should be included, people in the neighbourhood might think that the informant was so helpless or demanding that he or she needed massive support. Another reason was that I figured that it would be tiring for the informants to relate to me when they were not in their familiar environment. Instead, during field conversations I could ask about what the week end had been like, or I could ask what my informant was going to do this evening. Such topics are commonly discussed at work places and much information about the social lives of my informants could be gathered by participating in the ongoing conversations.

My experience is that participant observation can provide rich data material. But the problem is to remember. With a few exceptions, I did not take notes at the settings. I think that would have been too disturbing, and I would miss much of what was happening. I tried to memorise and to write down what Emerson, Fretz & Shaw (1995) call jottings at once when I left the setting. It is easier for me to remember how things and persons look like and what they are doing than what they are saying. I therefore had to concentrate on some of the dialogues in order to also get a picture of the conversations, themes and the way people spoke with each other. This was a difficult process for me and something I really have to improve in later projects.

## **Interviews**

In my study I have used participant observation as my main method. Therefore I have been talking most about observation in this paper. But I also used some semi-structured interviews in order to get a deeper understanding of the phenomena I was preoccupied with. For instance, I could ask about things that demanded more reflections. Interviews with people with intellectual disabilities are not always easy to perform. Some speak in a way that is not too easy to understand, and some may have difficulties in understanding what they are asked about. The literature also describe so called “interviewer effects”, for instance that the informants tend to answer what they think that the researcher wants them to. Because my study lasted for two years I had the opportunity to get to know my informants well and by and by we were able to develop a confident relationship. I also knew the context that we were reflecting about and I therefore could ask in concrete ways about the themes I wanted them to elaborate. Even so, I often experienced that my questions were much longer than the informants’ answers I therefore had to ask again from another angle to get a more detailed answer to my question. In such situations I was able to use our common experience as an interview guide.

Interviews are more researcher led than observations due to the fact that the researcher often has questions that one wants people to answer. But good interviews will also give the informant time and possibilities to give their own points of view and also to talk about what they think is important. An interview is not only a conversation. It is important as an interviewer also to be able to observe; the context, the mood the informant seems to be in, the relation between researcher and informant and one’s own role as an interviewer, chosen and ascribed. An interview is however, an artificial situation, and the interviewer does not necessarily know the context from which the informant speaks. One has to relate to the words that are spoken and how the informant thinks about the questions at that particular time. If one interviews in peoples’ homes or at their work places, one has the opportunity to observe the informant in one context of his or her daily life. That is an advantage, even if it is limited compared to doing participant observation.

One great advantage about interviewing is that it is easier to take notes during the conversation. Thus one gets much more information about what is being said than when one is observing. One even has the opportunity to use tape, and thus one is able to listen directly to statements, ways of speaking, signs of what mood the person was in etc. Thus, what is going on in interviews is easier to remember.

### **Conclusion**

It may seem from my presentation as if I value observation more than interviews. That is not the case. The fact is that I have more experience from being an observer than being an interviewer. Both methods have their pros and cons and the methods one uses are always dependent on one’s research questions. I will conclude, however, that there is seldom observation without conversation and there should be no qualitative interviews without simultaneous observation. I think it is important for us as researchers to discuss our methods and their convenience when people with intellectual disabilities are informants.

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